

SENATE Public Health
Exhibit No. 1
Date 4-10-2013
Bill No. HB 489

Montana Health Care Database Advisory Council

Report of Recommendations to the
Commissioner of Securities and Insurance
As Per Montana Legislative Study Bill HB573

August 2012

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EXECUTIVE SUMMARY:

Background

Montanans spend about \$7 billion annually on health care, which represents about 18% of our annual state gross domestic product. Costs for health care service spiral upward every year at a rate higher than general inflation, and higher than growth in both our domestic product and wages. Everyone feels it – health care takes a greater and greater percentage of what we have to spend, and leaves less for everything else. On top of rising costs, experts have estimated that around 30% of the total dollars spent on health care do not improve the health of patients.¹⁰⁾

Health care consumes approximately 23% of our state budget, and our state health care expenditures increase at a much higher rate - around 8% - than either inflation or wage growth. The state health programs that comprise the bulk of state health expenditures (Medicaid, Healthy Montana Kids, and the state employee health plan) are expected to cost \$1.1 to \$1.2 billion in each year of the current biennium. While the growth rates in state health costs are similar to those in the commercial health care market, they are clearly unsustainable in the long run, both in our state budget and in the broader economy.

Across the country, states are struggling to gain a better understanding of their health care systems and to manage both the cost and quality of those systems. But health care systems are not transparent. Our historical third party payment structure creates disconnects between patients and costs, price and quality, and between decision makers and the information needed to make better health choices.

If we are to do better at managing our health care systems, and using our health care dollars more effectively, we must have a comprehensive data set of health costs and expenditures. It has been said many times: you can't manage what you can't measure. Also, in order for market systems to be successful, information concerning health care cost, quality, and treatment effectiveness needs to be widely available to the public.

All Payer Claims Databases

All payer claims databases (APCDs) are a rapidly emerging and powerful tool in helping states to create transparency regarding health care pricing, quality, and utilization. Fourteen states have already implemented APCDs, including our neighbors in Colorado, Utah and Oregon; and

many more states are considering their implementation. The National Governor's Association has called for their development in all 50 states.

An APCD is a database that includes data from medical, eligibility, provider, pharmacy, and dental files; from both private and public payers of medical insurance claims. Payers contributing data typically include insurance carriers, Medicare and Medicaid, third party administrators, health plans, and pharmacy benefit managers.

APCDs provide a variety of benefits in managing health care system costs and promoting value. They provide the data necessary to evaluate critical issues such as regional variations in utilization, quality and cost. They can be used to study the impact of reimbursement methodologies and public health interventions. They can provide the data to do meaningful comparative effectiveness research. They can also be a key source to inform and support policy decisions, and drive health care system improvement.

Who Uses APCDs, and in What Ways?

Policy makers can use the database to identify areas of disparity in costs and outcomes, identify high performing areas and best practices to spur improvements in low performing areas, to understand and address utilization issues, to compare public system reimbursement (Medicaid, Medicare) to commercial payments, to identify regional variations in care, detect and reduce fraud in publicly funded health systems, and much more.

Medical providers are able to review their costs and outcomes across their entire range of patients, and not just those covered by one plan. They will be able to compare their results and costs to their peers across the state, develop best practices, and provide improved services to the public at a lower cost.

Insurers and health plans are better able to identify variability in costs and outcomes, detect fraud and abuse, and can use APCD data to assist with both contract and benefit design that identifies and rewards high value providers.

Businesses purchasing insurance are able to identify cost and quality indicators for the providers in their plans' networks, helping them to evaluate their health care expenditures,

compare their experience to others, and choose the best plans and benefits for their business needs.

Consumers are able to compare costs, quality measures and benefits among and across providers and make more informed choices about providers and health plans. The APCD will assist in creating the transparency necessary to develop a health care marketplace.

Researchers, such as those at our universities, are able to use APCDs for a wide range of public health and health system research projects.

These are but a few of the wide and varied uses of the consolidated data that can only be provided through a statewide data repository.

HB 573: To Study Creation of a Montana APCD

The 2011 legislature passed HB 573, an act to study the creation of an APCD in Montana. The study was assigned to the Commissioner of Securities and Insurance, and called for the formation of an advisory council to “review the costs, benefits, and procedural and technical requirements necessary to design, implement, and maintain a statewide all-payer all claims database for health care.”

Commissioner Lindeen appointed a council comprised of key stakeholders including insurers, medical providers, consumer representatives, business representatives, and state policy makers. The council has been meeting monthly since December of 2011, and has studied the implementation of APCDs in other states, along with the costs and benefits of implementing an APCD in Montana.

The advisory council has adopted a mission statement for a Montana APCD. It states: “the goal of the Montana Health Care Database is to provide a comprehensive, accurate, and transparent picture of our health care system. It will be a resource for improving health care system performance and value, and will create the ability for policy makers, consumers, insurers, providers and employers to make more informed and cost effective health care choices.”

The council has also adopted a set of governing principles, and technical scope and attributes statements that will guide the development of the database. These principles include the

confidentiality of and protection of health information, the adoption of national standards for datasets where possible, the recognition of the need for a phased-in approach to data collection, and a governance structure for the database.

This Report

The bulk of this report summarizes the work and recommendations of the APCD Advisory Council. It includes background information on claims data and analytical tools; clinical data and uses; research implications; value to the insurance marketplace; confidentiality of data; and the guiding principles for the APCD adopted by the Council.

HEALTH CARE CLAIMS PAYMENT DATA:

A truly comprehensive APCD, designed to serve the needs of a variety of potential users, will require several diverse data sets. However, the initial focus of a successful APCD needs to concentrate on claims payment information. The advantages of accessibility, standardization and clinical information which are contained in claims data are why all current state-initiated APCDs start by collecting claims payment data.

Major medical and pharmacy claim data are the backbone for APCD data aggregation and analytics. They provide transaction information for professional, institutional, and pharmacy claims between providers and claims processors, including third party administrators and insurance carriers (payers). Almost all health services provided in the United States create a financial claim for payment, virtually assuring that a record for that specific health-related patient encounter is created.

Successful APCDs combine data from all payers, providing invaluable statewide information on cost, quality, and utilization patterns. They also provide sufficient numbers for each and every provider to make meaningful comparisons. Many APCD data strategies also include the collection of claim-based information on insurance plans' enrollment; including membership, demographic statistics and benefit information.

This combination of data allows for research on both access and barriers to care, as well as numerous other health care measures. When these data are made publicly available, consumers and purchasers have the tools they need to compare prices and quality as they

make health care decisions. APCDs are proving to be powerful tools for all stakeholders in states where they are being used, filling in longstanding gaps in health care information.

As with all data sets, there are limitations to APCD data, however, capturing this information from patient care encounters creates an accessible and powerful information source. Each coverage type has its own set of claims data, including **Medical, Pharmacy, Dental,** and **Vision**, and each vary by the level of detail of the data that is submitted, processed and stored.

Medical Claims Data – Almost every health encounter creates a claim for payment, and evolving versions of standardized medical coding have created data that is even more comprehensive and useful than previously created medical claims data. New code formats have the ability to reflect greater detail within the code, more specific information about the diagnosis, and provide more flexibility for new technologies and diagnoses.

Pharmacy Claims Data - Pharmacy claims data contains the National Drug Code (NDC) which is a drug product classification system. The NDC was first used as part of a Medicare outpatient drug reimbursement plan. Today the NDC has spread to many other sectors of the health care industry including hospitals, managed care organizations, pharmaceutical manufacturers, and Medicaid. Its uses include clinical patient profile screening, inventory control, and drug claims processes.

Dental Claims Data - Dental claims data contains less clinical information than vision or medical claims, nevertheless the value of that information is still remarkable and has been well described.¹⁾ Minimum benefit packages covered by health plans may soon include certain oral health care procedures, therefore increasing the amount of dental claims data available. This would also put more emphasis on generating, transmitting and storing additional clinical information from dental claims.

Vision Claims Data - Vision claims data contain valuable diagnostic, utilization, and cost information. However because vision claims may be paid differently from other types of claims, and not all benefit plans cover vision services, they are rarely aggregated. Additionally recent clinical studies find that many chronic diseases are first identified through a common eye exam,

creating a further reason for including vision claims data in the claims aggregation process.

Claims Data Summarized: Many APCDs have recognized the value and shortcomings of collecting claims data. Therefore, planning a phased approach to aggregating all available information into one database is a universal strategy. The common availability of claims data, and the less available nature of other data (such as clinical), has prompted APCDs to begin with aggregating claims data.

CLINICAL DATA:

Clinical data, in its broadest sense, includes all information derived from a provider's medical interaction with a patient: history - including medications, allergies, problem list; physical examination findings; laboratory; and all other diagnostic testing. This information comprises the provider's patient record. In the past all of this information was on paper. It is now in the process of moving almost entirely to an electronic format, making that information available for electronic exchange, aggregation and analysis. Electronic exchange and use of clinical data is subject to the strictest security and privacy controls.

An APCD traditionally includes only administrative (claims) data gathered from health care payers and other sources. A comprehensive review of administrative data systems noted that "The principle disadvantage of administrative data is that one is limited to the data elements that were introduced, almost always for a totally different purpose. This has become particularly pertinent as hospitals and other providers are being compared based upon the 'outcomes' of care."²⁾

A 2006 Agency for Healthcare Research and Quality (AHRQ) report "Adding Clinical Data Elements to Administrative Data for Hospital-Level Reporting" concluded that "The results of this study demonstrate that selected clinical laboratory data elements added to administrative data can improve the accuracy of the risk adjustment models for comparing hospital mortality rates."³⁾

In 2008 AHRQ stated that "Providing clinical detail within administrative data records will enhance the ability to report publicly on the quality and cost of care, as well as improve the accuracy, transparency, research capacity, and value of administrative data."⁴⁾

A 2009 AHRQ Results Final Report, *Adding Clinical Data to Statewide Administrative Data: Pilot Project*, concluded that "The findings of this pilot project demonstrate that clinical data, when combined with the 'Present on Admission' indicator and administrative inpatient data, can be used to improve the risk adjustments models to better predict the risk of patient mortality" ⁵⁾

In addition to the AHRQ work, much additional research in many different settings has specifically demonstrated the value of combining clinical data with administrative data. ⁶⁾

Despite much strong evidence in favor of combining clinical and administrative data, such integration remains uncommon outside of specifically funded research settings. Of the statewide APCDs reviewed by the APCD Advisory Council none currently include clinical data. The final report from The Agency for Health Care Administration (AHCA) - Florida Center for Health Information and Policy Analysis explains part of the reason, in detailing its participation in the 2009 AHRQ Project: "Since laboratory test results are not currently collected in administrative data, there will be considerable effort and cost associated with any mandate to report laboratory test results." ⁷⁾

Although the Florida comment is specific to laboratory results as an example of clinical data, the effort and cost required to include broader clinical data with administrative data in an Integrated Data Repository (IDR) would be expected to be even greater. The reason is that all of the different clinical data sources would have to be independently interfaced with the IDR.

Another reason APCDs are not collecting clinical data is the high percentage that is not currently available in an electronic format. A 2011 National Center for Health Statistics brief reported that only 38.3 percent of office-based physicians in Montana reported having a system that meets the federal criteria for a basic system. ⁸⁾ Adoption of Electronic Health Record (EHR) systems is increasing, but this fact shows why incorporating clinical data into a Montana APCD might be reserved for a future phase.

The advent of statewide Health Information Exchanges (HIE), with the HIE serving to aggregate statewide clinical data, is eliminating this cost barrier. A December 2010 AHRQ report, *Future Directions for the National Healthcare Quality and Disparities Reports*, stated that "Although surveys and administrative databases are enormously valuable, measuring outcomes often requires detailed clinical data collected at the point of care ... there is potential for data linkages between health information exchanges (HIEs) and APCD databases." ⁹⁾

This potential for clinical HIE data to support administrative data is currently recognized in Montana. The Montana Blue Cross Blue Shield Patient Centered Medical Home infrastructure will combine clinical data with administrative data; as will the developing Rocky Mountain Health Network and Employee Benefit Management Services partnership, to develop an Accountable Health Network. Two other organizations currently collecting and analyzing clinical data are HealthShare Montana and the Montana Association of Health Care Purchasers.

Payer and health care organizations are increasingly being held to higher levels of accountability for health care quality and costs. Each possesses data with powerful potential to assist one another in accomplishing shared goals. A combined view of clinical data from health care organizations and administrative data from payers has the potential to generate a far more comprehensive view of health care quality, patient outcomes and costs than can either set of data independently. Combining clinical and administrative information has synergistic potential to exponentially increase the power contained within these large pools of data. Ultimately, the public will benefit as the path to a more affordable and sustainable health care system is illuminated, by the sophisticated use of combined clinical and administrative data.

The APCD Advisory Council has broadened the APCD concept by suggesting that Montana's effort be called the "Montana Health Care Database". What would this integration of clinical and administrative data actually mean for Montana users, which includes: patients, providers, payers and researchers? An Integrated Data Repository will allow various disparate data sources (i.e. clinical data, administrative data, pharmacy data, lab data, optometry office data, dental office data, census data, etc.) from across the state to be consolidated. The aggregated data will support research and analysis that can be used to pursue and optimize the triple aim of improving patient health care, improving population health and reducing per capita cost.

RESEARCH OPPORTUNITIES:

Over the last 30 years personal health care spending in the state of Montana has increased at an average annual rate of 8.4 percent, above the national average annual growth rate of 8.1 percent. At this rate of growth, spending on health care by Montanans is doubling every eight years, while per capita personal incomes are doubling only every 16 years. For a state where

personal health care spending accounts for 18 percent of the state's entire gross domestic product, understanding what is behind this rate of growth is imperative.

While we may know how fast health care spending is increasing, we know very little about why it is increasing. These gaps in knowledge limit our ability to identify and address the factors behind rising health care costs. Data on Montana's health care delivery system is needed to provide robust information about the cost and performance of Montana's health care delivery system. APCDs provide an opportunity to develop health care reforms that address spiraling health care costs in Montana, while expanding access and improving public health.

APCDs nationally have shown that aggregating health care data provides a reliable data source for multiple stakeholders to use, to examine variations in efficiency, quality, safety and cost. These results can be shared with providers, purchasers, and consumers to support an environment to improve health care quality and efficiency. With price transparency, consumers can make more informed value-based choices, an option not available today.

Many APCD's have two types of data sets. One is a fully identified, HIPAA compliant, highly restricted and limited access administrative data set. This is used to support advanced research and payer/provider only access. More common however are payer blinded, patient de-identified and cost standardized data sets that are fairly unrestricted and available for public use. These data sets are used in a wide variety of applications, but all support policy or practice changes that improve quality, cost and access.

HOW OTHER STATES USE APCDs:

APCDs are used in many different ways by states. One of the first multiple-state uses was an evaluation conducted for Maine, New Hampshire, and Vermont. For a set population, utilization of services and insurance claims payments were compared between states, as well as among different areas within the states. Wide variations in the rate of health care utilization were found, as well as variations in claims payments per member per month. Also, variations in potentially avoidable emergency department visits were used to identify possible shortages in the availability of primary care physicians.

Vermont used its APCD to support enhanced insurance rate review activities. Massachusetts used theirs to identify the factors that explain why health care costs were increasing faster than general inflation. These cost trends were examined to inform policy discussions on care coordination, payment reform, and insurance product design. The study found, for instance, that there was wide variation in payments made by health insurers that was not explained by differences in the quality of care.

The most exhaustive studies to date come from New Hampshire, one of the first states to have an APCD. Their numerous studies include: the role of caesarian sections as an insurance cost driver, a thorough examination of the ambulance market, the educational value of price transparency efforts, relative costs between New Hampshire hospitals, and the relationship between increasing costs to consumers and increases in payments to providers.

Wisconsin used data from an APCD to study health care use by area, according to the first three digits of the zip code. New York studied outpatient care patterns and potentially avoidable emergency department visits. Massachusetts studied the relationship between provider costs and payer premium rates, the impact of payment and delivery system reforms, and the factors contributing to the rapid increase in health care costs.

As more states develop APCDs, the knowledge base and comparative statistics will increase. This will help to identify variation and best practices in transparency, health care reform efforts, and state and local health care policy.

MARKET-BASED CONSIDERATIONS:

APCDs provide valuable information about risk that insurers can use to more accurately develop health insurance rates in a guaranteed issue market where insurers must accept all individuals, regardless of their health status and may not exclude pre-existing conditions. Many previously uninsured individuals will be entering the insurance market in 2014. The APCD will assist insurers because it provides them with more information about their own risk pool in relation to the rest of the health insurance market.

APCD information is valuable for mechanisms such as risk adjustment that will redistribute risk across all the insurers who are selling within certain market segments. Availability of market

data is critical for understanding the impact of risk adjustment on health insurance issuers. An insurer cannot know the financial impact of the risk adjustment mechanism on their own book of business without knowing how their average risk score compares to the state-wide average risk score. Without this knowledge, uncertainties will likely lead insurers to make conservative assumptions and implement higher premiums. Understating premiums threatens solvency and overstating premiums could result in reduced enrollment and large premium refunds as a result of the minimum loss ratio law.

Self-funded employer health plans, even though not participating in risk adjustment, will find this information useful for setting contribution rates and analyzing the predicted risk assumed for upcoming plan years. The APCD will make claims costs more transparent than ever before, revealing trends in medical costs, as well as the cost-effectiveness of certain medical treatments. This information will assist employer health plans in created value-based designs for their health plans, thereby improving outcomes and reducing costs.

An APCD provides additional transparency for consumers, providing information about cost, as well as the effectiveness and safety of health care delivery provided by specific provider groups and hospitals. Consumers cannot assume responsibility for the cost and effectiveness of their health care without complete and accurate information.

Health care providers may use APCD information for setting competitive prices and to assist them in enforcing safe and effective outcomes across their work force. Many studies show that accountability and transparency greatly reduces medical error rates. Reducing medical errors saves lives and reduces costs.

Research conducted on data collected through APCDs may be used by states to develop an essential health benefits package that better meets the needs of its citizens by providing the most cost-effective health care. In addition, APCDs may utilize an IT infrastructure that can be integrated with health information exchange systems, thereby streamlining data collection and increasing its value.

GOVERNANCE:

The council collected information about government structures being used by other states for their APCDs. The council then adopted a "Mission and Principles" document in which they agreed that the governance structure should be as follows:

"The database should be administered by a quasi-governmental agency, which would be responsible for setting database guidelines, overseeing the development and implementation of the database, publishing reports, and providing the administration of the database, and setting security policies regarding access and use of the data."

The council agreed that the quasi-governmental entity should be administratively attached to a state agency. The Commissioner of Securities and Insurance (CSI) would enforce any possible penalties on insurance companies for failing to report data. Also, any required administrative oversight of the APCD should be delegated to the CSI. The APCD quasi-government entity would be attached to CSI because the primary data reporting in the first years would be from payers (insurers and third party administrators), but there would be a provision which assigns DPHHS the task of enforcing provider reporting, as that will be required in the future.

PROVIDER REPORTING:

Mandatory reporting on clinical and claims data by providers should be required, just as it is for payers. Within a reasonable time-frame, providers could be asked to report payment and/or write-off costs data for uninsured patients. Economists estimate a large increase, of approximately 10%, on premiums for the insured is caused by uncompensated care on the uninsured. By reporting on the uninsured, the APCD will be able to directly measure the impact of the uninsured on medical costs. This will be of great value to policy makers for understanding how the uninsured are cared for and how they affect overall costs.

In regards to clinical data; a common response to quality estimates based on claims data is that only clinical data can adequately measure quality. Claims data can determine, for example, if someone is being treated for high cholesterol from the diagnosis code on the medical claim, and the presence of a claim for cholesterol lowering medication. However, without the clinical data this approach cannot determine if the patient has achieved the desired results. For example, has the cholesterol level been successfully lowered to the recommended level.

The difficulty with clinical data reporting is that it is often in paper format. This is slowly being addressed with initiatives across the country to encourage computerization. We believe that clinical data reporting should be required, but that the requirement needs to be phased in over time. Providers who implement Electronic Medical Records (EMRs) now have significant incentives from the Center for Medicare and Medicaid Services (CMS). In a few years they will face significant penalties from CMS for failing to use an EMR system. An APCD could add to this by creating similar incentives.

SECURITY:

A critical component to the development of an APCD is the privacy and security of the data. The APCD would include data received from many different sources, including: health care providers, insurance companies, and third party administrators. Since this will represent the protected health and claims information of Montana consumers, data security and patient privacy laws and regulations are of paramount importance.

Covered entities (health insurance issuers, health care providers and health care clearinghouses) must comply with all aspects of the federal Health Information Portability and Accountability Act of 1996 (HIPAA), including the Standards for Privacy of Individually Identifiable Health Information, 45 CFR Parts 160 and 164, subparts A and E, (the "Privacy Standards"), the Security Standards for the Protection of Electronic Protected Health Information, 45 CFR Parts 160 and 164, subparts A and C, (the "Security Standards"). The APCD would probably be a "business associate" of many different covered entities and therefore would also have to comply with all aspects of HIPAA privacy. The Health Information Technology for Economic and Clinical Health Act, as incorporated in the American Recovery and Reinvestment Act of 2009 (the "HITECH Act") also applies.

HIPAA and HITECH set rules and standards for protected health information ("PHI") and electronic protected health information ("Electronic PHI"), which is information about health status, the provision of health care, or the payment for health care that can be linked to an individual. HIPAA creates administrative, physical, and technical safeguards around the data. HITECH addresses the privacy and security concerns associated with electronic transmission of health and claims information. It extends the privacy and security requirements to the business associates of entities treated as "covered entities" under HIPAA, and creates new breach

notification rules for instances where a breach of PHI or Electronic PHI has occurred. Finally, and critical to the implementation of an APCD, it extends current accounting and disclosure requirements to information that is used to carry out treatment, and to payment and health care operations when an organization is using an electronic health record.

The governing entity must ensure that all data is at all times transmitted and stored in a secure and encrypted manner. As further protection, any data intake and storage management system must be able to manage intake and processing without manual intervention. When the data is used to create reports, certain information about a patient or member in a dataset will be replaced with a unique identifier. HIPAA rules offer further guidance when reports based on APCD analysis are ready for publication. These rules guide researchers and report developers about what can and cannot be shown when the number of patients or members in a particular category falls below an established floor or minimum cell size.

In Montana, the right to individual privacy is constitutionally protected under Article 2, Section 10 of the Montana Constitution. The Montana Legislature recognized that health care information is personal and sensitive information that if improperly disclosed or released, could do significant harm to the individual and as a result, enacted the Uniform Health Care Information Act, which is codified in Title 50, Chapter 16, Part 5 of the Montana Code Annotated. There are also Montana Administrative rules adopted under the authority of the Title 50 that apply to the protection of PHI as well.

This Act ensures that those health care providers that may not be subject to the federal HIPAA privacy and security laws, must comply with certain protections for the use and disclosure of the confidential health information of individuals. Additionally, the Insurance Information and Privacy Protection Act, which is codified in Title 33, Chapter 19 of the Montana Code Annotated applies to insurers, insurance producers and insurance support organizations, and establishes standards for the collection, use and disclosure of information gathered during the course of insurance transactions involving the confidential and sensitive medical claims information of individuals. In addition, there are Administrative Rules of Montana supporting that chapter: ARM 6.6.6901, et. seq., "Insurance Information and Privacy Protection and ARM 6.6.7001, et. seq., "Insurance Standards for Safeguarding Personal Information."

To the extent that either the Uniform Health Care Information Act or the Insurance Information and Privacy Protection Act provide privacy and security protection beyond that required by HIPAA and HITECH, governing entity must ensure that those additional protections are provided. Additionally, Montana recognizes the individual's right privacy with respect to the collection of confidential personal information pertaining to that individual, and requires disclosure of any discovered breach of the security of a data system (Title 30, Chapter 14, Part 17 of the Mont. Code Ann.).

In addition, all corporations and business entities have a right to protection of their trade secrets pursuant to Title 30, Chapter 14, Part 4. The governing entity must also ensure that the APCD is managed within the constraints of all applicable rules regarding trade secrets for those organizations submitting data to the APCD.

The APCD will be either a hosted solution residing in a datacenter secured according to industry standards, or hosted in the governing entity's industry standards secured facility; either of which would be subject to safe harbor rules and be subject to HIPAA audits. To ensure the protection and security of PHI and Electronic PHI, the data center ultimately hosting the APCD should have characteristics similar to the following:

- Role-based database security framework, appropriately limiting access to APCD data and logging all activity based on user credentials.
- Encryption of data both in motion and at rest, incorporating HIPAA-compliant HTTPS, SSL, and NIST-approved hash algorithm.
- Firewall protection and intrusion prevention/detection, including logging of unauthorized access attempts.
- Daily backup of all data and datasets and storage of that data in encrypted form.
- Third-party data security audits.
- Secure data center facility characterized by 100% redundancy, secure/controlled access, and fault tolerance.
- Mandatory sign-in/-out and escorting of all visitors at all times.
- Data will be submitted to the data center using secure data transmission protocols.

When datasets are created for the purpose of developing reports both internally or externally through a formal data application or data request process, file formats, access, and transmission standards will be consistent with all required standards of HIPAA, HITECH, and Montana law.

An entity submitting data to the data center will have access to its own submitted PHI or Electronic PHI. Submitting entities will have access to the data submitted by other submitting entities only in de-identified format. The credentials (login and password) of the submitting and/or requesting entity will be used to determine the access level for each entity.

The governing entity administrative board will serve as the entity responsible for policy and the ongoing oversight of operations of the APCD, including any formal data application or data request process developed for reporting or research purposes.

COSTS AND FINANCES:

While health care cost databases can be useful tools in managing costs and quality, they do require investment. Costs include both one-time start up and implementation investments, and ongoing costs of database management, analytics, and reporting.

Some of the factors that affect the costs are the population covered, the number of payer sources, the number and types of data sources, the governance structure, security design, and analytics and reporting. Relatively speaking, Montana has low numbers in terms of population, payer sources, and the number and types of data sources, which could lower costs.

Additionally, as more health care cost databases have been developed across the country, there are more working models on which to start a Montana database, which will tend to mitigate costs. However, we proposed to include provider reporting of clinical data, which will add more data sources, and may increase the costs.

Start-up Costs - In a review of states with existing health care cost databases, we found the costs of developing and implementing those databases to average approximately \$1.1 million. In Colorado, the most recent state to develop a health care database, and one with a well thought out design, the cost was \$1.5 million. All of these databases capture administrative data, but have not added the clinical component we propose. Therefore, our start-up costs may be higher due to the addition of clinical data components. We anticipate the need for average

start up costs for the claims component - \$1.1 million, and up to an additional \$1.1 million to add the clinical components. However, the additional costs may prove to be far less than estimated if we can capitalize on existing data entities and platforms that already exist in Montana.

Ongoing Costs - Ongoing costs include those costs of administering the database, managing the data flow, providing the analytics, preparing reports, and providing governance to the effort. Ongoing costs in other states average about \$600K per year. Choices that affect the level of ongoing costs include governance structures, staffing levels, reporting choices, and analytical sophistication. We anticipate the need for the average level of ongoing costs for the Montana Health Care Database.

Funding Mechanisms - States use a variety of funding mechanisms for their health care cost databases. They include using general funds, assessments on payers and providers, Medicaid funds, private donations, federal, state and private grants, and sales of products and services. While sales of products and services may generate income over time, the advisory council believes that to guarantee ongoing funding, the Montana Health Care Database should seek funding from the Montana Legislature, and at the same time seek to reduce appropriated funds by seeking funding from state and private grant funds.

For the 2014-15 biennial, we anticipate the need for a biennial appropriation of approximately \$3.4 million for the implementation and operation of the database. Costs may be lower, however, depending on current vendor resources.

¹⁾ Clinical Performance Measures for Dental Care Plans” issued for Agency for Healthcare Research and Quality.

²⁾ Bradley, Herrin et al., 2006; Werner and Bradlow, 2006 –

(<http://www.esourceresearch.org/eSourceBook/AdministrativeDataSystems/1LearningObjectives/tabid/372/Default.aspx>).

³⁾ Final Report AHRQ Contract #233-02-0088, Task Order 13, Vol. 1, July 3, 2006

⁴⁾ <http://www.hcup-us.ahrq.gov/reports/clinical data.jsp>

⁵⁾ <http://www.hcup-us.ahrq.gov/datainnovations/clinicaldata/3MSummaryResultsReportFinal.jsp>.

⁶⁾ Shahian, Silverstein et al., 2006; Parker, Damberg et al., 2006; Austin and Tu, 2006

⁷⁾ <http://www.fhin.net/content/archive/#ui-tabs-4>

⁸⁾ U.S. Department of Health & Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics Data Brief No. 79, November 2011

⁹⁾ Rogers, 2009 AHRQ Publication No. 11-0026-EF, <http://www.ahrq.gov/research/iomqrdreport>

¹⁰⁾ High Level of Waste in Health Spending, Says Medicare and Medicaid Boss, <http://www.medicalnewstoday.com/articles/238654.php>, Reflections on Geographic Variations in U.S. Health Care http://www.dartmouthatlas.org/downloads/press/Skinner_Fisher_DA_05_10.pdf

Advisory Council Recommendations for the Montana Health Care Database

- The primary purpose of the Montana Health Care Data Base is to provide a rich source of data about our health care system, and to provide analytical capacity for stakeholders to better understand and improve that system regarding both quality and cost.
- The database will be most useful when it is populated by the most comprehensive set of health information available. Therefore, both payment data and clinical data will ultimately be captured.
- The data set for the database must be comprehensive, which is best achieved by a state mandate.
- Thresholds for the mandate should be set, both for payers and providers.
- The sources for the payment data should be as broad as possible, and should include commercial health insurance companies, pharmacy benefit managers, Medicaid, Healthy Montana Kids, third party administrators, the state employee health benefits system, Title 2 entities and claims clearinghouses.
- To the extent feasible, the database should include federal claims data from Montana, including data from Medicare, the federal employee health benefits system, the Indian Health Service, and Tricare.
- The sources for clinical data should include hospitals, provider groups, federally qualified health centers and rural health centers, individual providers, outpatient surgery centers, ASCs, freestanding labs and radiology centers, pharmacies and others.
- To the extent feasible, the clinical sources should also include the Veterans Administration, the Indian Health Service, and tribal and urban Indian health clinics.
- The database should develop methods for collecting data about the uninsured.
- The database should use national data collection standards, but should be flexible enough to include Montana specific standards where appropriate and reasonable.
- Recognizing that payers and providers are not all in the same stages of data capture, the database can and should be implemented in phases.
- The entities that provide data should have access to their own data, at a minimum; but access to information in the database must protect patient confidentiality and proprietary business information. Access to data must be limited to defined levels by type of entity.
- The data base should be administered by a quasi-governmental agency, which would be responsible for setting data base guidelines, overseeing the development and implementation of the database, publishing reports, and providing the administration of the database, and setting security policies regarding access and use of the data.

Technical Scope and Attributes Sub-Committee Recommendations for the Montana Health Care Database

- The system shall be developed and operated to fully protect the confidentiality of patient-identifiable information under the safeguards of legal standards, security protocols, access controls and access logging.
- Legislation should include a provision for stakeholder involvement to advise on data editing, and to ensure data quality, accuracy and reliability.
- The system should be developed and operated with considerations for minimizing the burden on data providers.
- Timeliness of data is an important consideration for identifying emerging patterns. Reporting frequency should balance this need with the workload requirement on submitters.
- The governing entity should seek historical data wherever available.
- Policies and procedures will be implemented to use, build and improve upon, and coordinate existing data sources and measurement efforts through the integration of data systems and standardization of concepts.
- In operating the system, the governing entity shall consider national standards where possible, but allow for additions as deemed necessary.
- Access to the entire dataset will be available in a de-identified format, subject to: protected patient confidentiality; proprietary business information rules; limits by defined levels by type of entity; and established policy. Each data provider will have full access to its own data. Analysis of the data by as many as possible should be encouraged, subject to confidentiality.
- At a minimum, the governing entity will provide a level of reporting and analysis for public consumption, following best practices for a consumer portal.

Claims Data – Additional Information

Medical Claims - Updates include the forthcoming and mandatory ICD-10-CM and ICD-10-PSC code sets, scheduled to be implemented in 2014. The differences between ICD-9 and ICD-10 are significant. The most obvious, however, is that ICD-10 codes document over 68,000 diagnoses, compared to only 14,000 ICD-9-CM codes.

The current system, International Classification of Diseases, 9th Edition, Clinical Modification (ICD-9-CM), does not provide the necessary detail for patients' medical conditions or the procedures and services performed on hospitalized patients. ICD-9-CM is 30 years old, has outdated and obsolete terminology, uses outdated codes that produce inaccurate and limited data, and is inconsistent with current medical practice. It cannot accurately describe the diagnoses and inpatient procedures of care delivered in the 21st century.

Pharmacy Claims - Two configurations of NDC exist, a ten and an eleven digit configuration. A majority of health care organizations and government agencies use the eleven digit code format. The first segment of the code identifies the labeler/manufacture code. The next segment, the product code, has information regarding drug strength, dosage form, and formulation. The last segment of the code, the package code, refers to package size and type.

These three segments yield information for any medication; including generic name or active ingredient, the manufacturer, the strength, route of administration, package size, and trade name. Providers of analytics software, including John Hopkins University, Verisk, OptumInsight, and NCQA have used NDC codes to derive meaningful clinical information related to cost, risk, quality, and outcomes measures.

Significant clinical value may also be added through the use of the Anatomical Therapeutic Chemical (ATC) codes adopted by the World Health Organization. In the ATC classification system, drugs are divided into categories based on the organ or system on which they act and their chemical, pharmacological and therapeutic properties. The availability of these codes can add significant clinical value to existing claims information. A more commonly used system of coding in the United States is the Generic Product Index (GPI), there are crosswalks available to link GPI and ATC codes.

HEALTH INSURANCE

Bitter Pill: Why Medical Bills Are Killing Us

By Steven Brill | Feb. 20, 2013

Corrections Appended: February 26, 2013

1. Routine Care, Unforgettable Bills

When Sean Recchi, a 42-year-old from Lancaster, Ohio, was told last March that he had non-Hodgkin's lymphoma, his wife Stephanie knew she had to get him to MD Anderson Cancer Center in Houston. Stephanie's father had been treated there 10 years earlier, and she and her family credited the doctors and nurses at MD Anderson with extending his life by at least eight years.

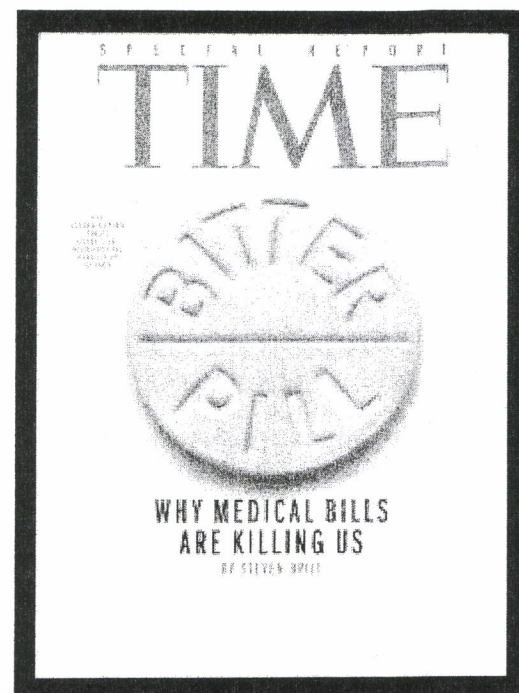
Because Stephanie and her husband had recently started their own small technology business, they were unable to buy comprehensive health insurance. For \$469 a month, or about 20% of their income, they had been able to get only a policy that covered just \$2,000 per day of any hospital costs. "We don't take that kind of discount insurance," said the woman at MD Anderson when Stephanie called to make an appointment for Sean.

Stephanie was then told by a billing clerk that the estimated cost of Sean's visit — just to be examined for six days so a treatment plan could be devised — would be \$48,900, due in advance. Stephanie got her mother to write her a check. "You do anything you can in a situation like that," she says. The Recchis flew to Houston, leaving Stephanie's mother to care for their two teenage children.

About a week later, Stephanie had to ask her mother for \$35,000 more so Sean could begin the treatment the doctors had decided was urgent. His condition had worsened rapidly since he had arrived in Houston. He was "sweating and shaking with chills and pains," Stephanie recalls. "He had a large mass in his chest that was ... growing. He was panicked."

Nonetheless, Sean was held for about 90 minutes in a reception area, she says, because the hospital could not confirm that the check had cleared. Sean was allowed to see the doctor only after he advanced MD Anderson \$7,500 from his credit card. The hospital says there was nothing unusual about how Sean was kept waiting. According to MD Anderson communications manager Julie Penne, "Asking for advance payment for services is a common, if unfortunate, situation that confronts hospitals all over the United States."

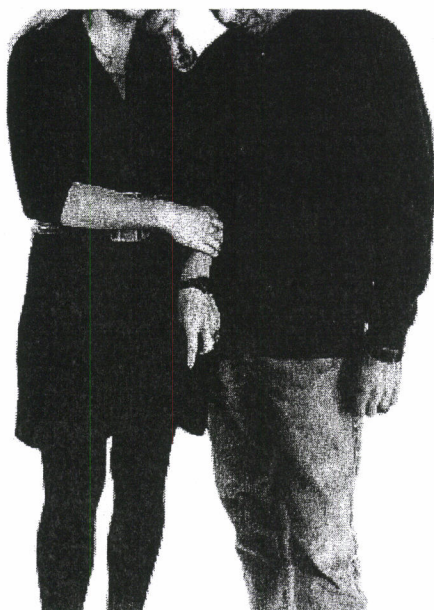
The total cost, in advance, for Sean to get his treatment plan and initial doses of chemotherapy was \$83,900.



Why?

By:

Approved For
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BY Chuck Hunter



CLAUDIA SUSANA FOR TIME

Sean Recchi

Diagnosed with non-Hodgkin's lymphoma at age 42. Total cost, in advance, for Sean's treatment plan and initial doses of chemotherapy: \$83,900. Charges for blood and lab tests amounted to more than \$15,000; with Medicare, they would have cost a few hundred dollars

The first of the 344 lines printed out across eight pages of his hospital bill — filled with indecipherable numerical codes and acronyms — seemed innocuous. But it set the tone for all that followed. It read, "1 ACETAMINOPHE TABS 325 MG." The charge was only \$1.50, but it was for a generic version of a Tylenol pill. You can buy 100 of them on Amazon for \$1.49 even without a hospital's purchasing power.

(In-Depth Video: The Exorbitant Prices of Health Care)

Dozens of midpriced items were embedded with similarly aggressive markups, like \$283.00 for a "CHEST, PA AND LAT 71020." That's a simple chest X-ray, for which MD Anderson is routinely paid \$20.44 when it treats a patient on Medicare, the government health care program for the elderly.

Every time a nurse drew blood, a "ROUTINE VENIPUNCTURE" charge of \$36.00 appeared, accompanied by charges of \$23 to \$78 for each of a dozen or more lab analyses performed on the blood sample. In all, the charges for blood and other lab tests done on Recchi amounted to more than \$15,000. Had Recchi been old enough for Medicare, MD Anderson would have been paid a few hundred dollars for all those tests. By law, Medicare's

payments approximate a hospital's cost of providing a service, including overhead, equipment and salaries.

On the second page of the bill, the markups got bolder. Recchi was charged \$13,702 for "1 RITUXIMAB INJ 660 MG." That's an injection of 660 mg of a cancer wonder drug called Rituxan. The average price paid by all hospitals for this dose is about \$4,000, but MD Anderson probably gets a volume discount that would make its cost \$3,000 to \$3,500. That means the nonprofit cancer center's paid-in-advance markup on Recchi's lifesaving shot would be about 400%.

When I asked MD Anderson to comment on the charges on Recchi's bill, the cancer center released a written statement that said in part, "The issues related to health care finance are complex for patients, health care providers, payers and government entities alike ... MD Anderson's clinical billing and collection practices are similar to those of other major hospitals and academic medical centers."

The hospital's hard-nosed approach pays off. Although it is officially a nonprofit unit of the University of Texas, MD Anderson has revenue that exceeds the cost of the world-class care it provides by so much that its operating profit for the fiscal year 2010, the most recent annual report it filed with the U.S. Department of Health and Human Services, was \$531 million. That's a profit margin of 26% on revenue of \$2.05 billion, an astounding result for such a service-intensive enterprise.¹

The president of MD Anderson is paid like someone running a prosperous business. Ronald DePinho's total compensation last year was \$1,845,000. That does not count outside earnings derived from a much publicized waiver he received from the university that, according to the *Houston Chronicle*, allows him to maintain unspecified "financial ties with his three principal pharmaceutical companies."

(SHARE YOUR THOUGHTS: Are Medical Bills Too High? Tell Us Here)

DePinho's salary is nearly two and a half times the \$750,000 paid to Francisco Cigarroa, the chancellor of entire University of Texas system, of which MD Anderson is a part. This pay structure is emblematic of American medical economics and is reflected on campuses across the U.S., where the president of a hospital or hospital system associated with a university — whether it's Texas, Stanford, Duke or Yale — is invariably paid much more than the person in charge of the university.

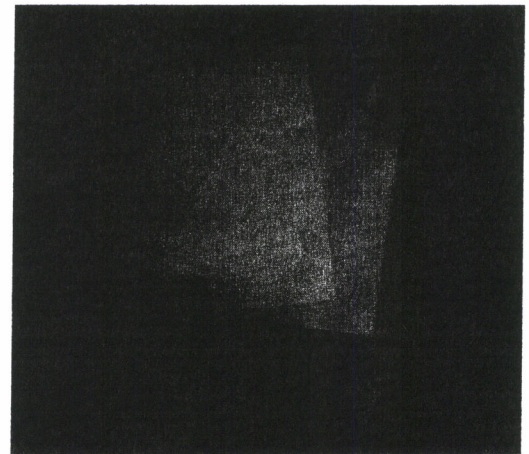
I got the idea for this article when I was visiting Rice University last year. As I was leaving the campus, which is just outside the central business district of Houston, I noticed a group of glass skyscrapers about a mile away lighting up the evening sky. The scene looked like Dubai. I was looking at the Texas Medical Center, a nearly 1,300-acre, 280-building complex of hospitals and related medical facilities, of which MD Anderson is the lead brand name. Medicine had obviously become a huge business. In fact, of Houston's top 10 employers, five are hospitals, including MD Anderson with 19,000 employees; three, led by ExxonMobil with 14,000 employees, are energy companies. How did that happen, I wondered. Where's all that money coming from? And where is it going? I have spent the past seven months trying to find out by analyzing a variety of bills from hospitals like MD Anderson, doctors, drug companies and every other player in the American health care ecosystem.

When you look behind the bills that Sean Recchi and other patients receive, you see nothing rational — no rhyme or reason — about the costs they faced in a marketplace they enter through no choice of their own. The only constant is the sticker shock for the patients who are asked to pay.

Yet those who work in the health care industry and those who argue over health care policy seem inured to the shock. When we debate health care policy, we seem to jump right to the issue of who should pay the bills, blowing past what should be the first question: Why exactly are the bills so high?

What are the reasons, good or bad, that cancer means a half-million- or million-dollar tab? Why should a trip to the emergency room for chest pains that turn out to be indigestion bring a bill that can exceed the cost of a semester of college? What makes a single dose of even the most wonderful wonder drug cost thousands of dollars? Why does simple lab work done during a few days in a hospital cost more than a car? And what is so different about the medical ecosystem that causes technology advances to drive bills up instead of down?

(iReport: Tell Us Your Health Care Story)



PHOTOGRAPH BY NICK VEASEY FOR TIME

Gauze Pads: \$77

Charge for each of four boxes of sterile gauze pads, as itemized in a \$348,000 bill following a patient's diagnosis of lung cancer

Recchi's bill and six others examined line by line for this article offer a closeup window into what happens when powerless buyers — whether they are people like Recchi or big health-insurance companies — meet sellers in what is the ultimate seller's market.

The result is a uniquely American gold rush for those who provide everything from wonder drugs to canes to high-tech implants to CT scans to hospital bill-coding and collection services. In hundreds of small and midsize cities across the country — from Stamford, Conn., to Marlton, N.J., to Oklahoma City — the American health care market has transformed tax-exempt “nonprofit” hospitals into the towns' most profitable businesses and largest employers, often presided over by the regions' most richly compensated executives. And in our largest cities, the system offers lavish paychecks even to midlevel hospital managers, like the 14 administrators at New York City's Memorial Sloan-Kettering Cancer Center who are paid over \$500,000 a year, including six who make over \$1 million.

Taken as a whole, these powerful institutions and the bills they churn out dominate the nation's economy and put demands on taxpayers to a degree unequaled anywhere else on earth. In the U.S., people spend almost 20% of the gross domestic product on health care, compared with about half that in most developed countries. Yet in every measurable way, the results our health care system produces are no better and often worse than the outcomes in those countries.

According to one of a series of exhaustive studies done by the McKinsey & Co. consulting firm, we spend more on health care than the next 10 biggest spenders combined: Japan, Germany, France, China, the U.K., Italy, Canada, Brazil, Spain and Australia. We may be shocked at the \$60 billion price tag for cleaning up after Hurricane Sandy. We spent almost that much last week on health care. We spend more every year on artificial knees and hips than what Hollywood collects at the box office. We spend two or three times that much on durable medical devices like canes and wheelchairs, in part because a heavily lobbied Congress forces Medicare to pay 25% to 75% more for this equipment than it would cost at Walmart.

The Bureau of Labor Statistics projects that 10 of the 20 occupations that will grow the fastest in the U.S. by 2020 are related to health care. America's largest city may be commonly thought of as the world's financial-services capital, but of New York's 18 largest private employers, eight are hospitals and four are banks. Employing all those people in the cause of curing the sick is, of course, not anything to be ashamed of. But the drag on our overall economy that comes with taxpayers, employers and consumers spending so much more than is spent in any other country for the same product is unsustainable. Health care is eating away at our economy and our treasury.

The health care industry seems to have the will and the means to keep it that way. According to the Center for Responsive Politics, the pharmaceutical and health-care-product industries, combined with organizations representing doctors, hospitals, nursing homes, health services and HMOs, have spent \$5.36 billion since 1998 on lobbying in Washington. That dwarfs the \$1.53 billion spent by the defense and aerospace industries and the \$1.3 billion spent by oil and gas interests over the same period. That's right: the health-care-industrial complex spends more than three times what the military-industrial complex spends in Washington.

When you crunch data compiled by McKinsey and other researchers, the big picture looks like this: We're likely to spend \$2.8 trillion this year on health care. That \$2.8 trillion is likely to be \$750 billion, or 27%, more than we would spend if we spent the same per capita as other developed countries, even after adjusting for the relatively high per capita income in the U.S. vs. those other countries. Of the total \$2.8 trillion that will be spent on health care, about \$800 billion will be paid by the federal government through the Medicare insurance program for the disabled and those 65 and older and the Medicaid program, which provides care for the poor. That \$800 billion, which keeps rising far faster than inflation and the gross domestic product, is what's driving the federal deficit. The other \$2 trillion will be paid mostly by private health-insurance companies and individuals who have no insurance or who will pay some portion of the bills covered by their insurance. This is what's increasingly burdening businesses that pay for their employees' health insurance and forcing individuals to pay so much in out-of-pocket expenses.

1. Here and elsewhere I define operating profit as the hospital's excess of revenue over expenses, plus the amount it lists on its tax return for depreciation of assets—because depreciation is an accounting expense, not a cash expense. John Gunn, chief operating officer of Memorial Sloan-Kettering Cancer Center, calls this the "fairest way" of judging a hospital's financial performance

The original version of this article misidentified William Powers Jr., the president of the University of Texas system, as the head of the entire system. That is in fact Francisco Cigarroa, the chancellor of the University of Texas

Breaking these trillions down into real bills going to real patients cuts through the ideological debate over health care policy. By dissecting the bills that people like Sean Recchi face, we can see exactly how and why we are overspending, where the money is going and how to get it back. We just have to follow the money.

Colorado All Payer Claims Database Privacy, Security and Data Release Fact Guide



CENTER FOR IMPROVING
VALUE IN HEALTH CARE

All Payer Claims Database: Background

The Colorado All Payer Claims Database (APCD) collects health insurance claims from public and private payers into a secure database. Created by legislation in 2010 and administered by the Center for Improving Value in Health Care (CIVHC), the APCD is Colorado's most comprehensive source for information about health care spending and utilization in Colorado. As of January 2013, the APCD includes health insurance claims from Medicaid and the eight largest health plans for the individual and large group fully-insured markets. These claims represent more than 2.5 million Colorado residents, or over 50 percent of the insured population in the state. By the end of 2014, the APCD is projected to include claims information for remaining segments of the commercial market as well as Medicare, eventually reflecting the vast majority of insured Coloradans.

APCD Security and Data Availability: Summary

In accordance with Colorado Department of Health Care Policy and Finance (HCPF) rules (10 CCR 2505-5-1.200.5), CIVHC is required to ensure the APCD follows all HIPAA privacy and security requirements for the protection of patient information. Claims information in the APCD is always encrypted, both in transmission and while stored, and resides on secure servers which undergo systematic ongoing testing for security. Only high-level aggregated information is available on the public APCD website (www.cohealthdata.org); **no** individual or personal information may be seen on the APCD site.

Limited release of APCD data is allowable under the established HCPF rules, provided Health Insurance Portability and Accountability Act (HIPAA) privacy and security requirements are strictly enforced and the purpose of the data request meets the goals of the Triple Aim for Colorado: better health, better care and lower costs. The HCPF rules require that a multi-stakeholder Data Release Review Committee (DRRC) review data requests and advise the Administrator whether such requests meet these criteria and will contribute to better health for Coloradans.

APCD Security and Data Availability: Detailed Q&A

Who decides who can get information from the APCD? What rules do they use?

The APCD governance rules promulgated by HCPF require that the DRRC develop protocols for the release of APCD data. The DRRC comprises health care data and analytical experts representing a variety of organizations and stakeholder perspectives. The rules require that the DRRC review the request and advise the Administrator on whether release of the data is consistent with the statutory purpose of the APCD, will contribute to efforts to improve health care or public health outcomes for Colorado residents, complies with the requirements of HIPAA and will employ appropriate analytical methods. Requests must meet all these criteria in order to be recommended for approval. Approved data requests then require the requestor to enter into a very strict Data Use Agreement. Additionally,

the APCD Administrator is required to report annually to HCPF listing data requests, their purpose and how they meet HIPAA requirements.

What kind of information can organizations get from the APCD?

By rule, the APCD Administrator is permitted to provide or “release” data at varying levels of detail and specificity. All releases of APCD data must meet all HIPAA privacy and security requirements and are subject to DRRC approval, which requires that the intended use supports reaching the Colorado Triple Aim of better health, better care, and lower costs. For example, public and private entities may request information on costs associated with treatment of a specific diagnosis or disease by region or county, variation in the cost of common procedures by facilities, and utilization of high cost services such as MRIs for a defined population.

Are there limitations on the data that organizations can get from the APCD?

Yes, APCD data releases are subject to both HIPAA privacy and security requirements and state legal and regulatory restrictions to protect privacy:

1. In keeping with the “minimum necessary” standard established under HIPAA, applicants must demonstrate need and provide justification for each data element requested. The DRRC will recommend and the APCD Administrator will release only those data elements which are absolutely necessary to accomplish the applicant's intended use.
2. Protected Health Information (PHI) may only be released in limited circumstances for public health, health care operations and pre-approved research purposes, and can never be shared publicly as a result of a research project or program.
3. Applicants may be required to show written approval from an Institutional Review Board or a Privacy Board as part of the Application.
4. As part of the Data Use Agreement, all Applicants must provide written assurances that:
 - Data will be used only for the purpose stated in the approved Application.
 - No attempt will be made to use any APCD data supplied to ascertain the identity of specific insured individuals or patients, or to report data or results at a level of detail that could permit a reader to ascertain the identity of specific insured individuals or patients, nor will downstream linkages to outside data sources occur without specific authorization from the APCD Administrator.
 - Restricted data elements such as PHI will not be released except as specifically approved in the original Application and Data Use Agreement.
 - The Applicant will obtain these assurances in writing from any recipient of the data or agent that processes data on behalf of the Applicant.
 - The data will not be re-released in any format to anyone except personnel identified and approved in the original Application and Data Use Agreement.

What information is required in order to submit a data request?

According to both APCD statute and HCPF rules, all data release applications must be submitted in writing and describe in detail:

- The purpose of the project and intended use of the data.
- Methodologies to be employed.
- Type of data and specific data elements requested along with justification.
- Qualifications of the research entity requesting the data.
- The specific Privacy and Security measures that will be employed to protect the data.
- Description of how the results will be used, disseminated or published.

The DRRC reviews the written data release applications and advises the APCD Administrator on the appropriateness of the request and whether release of the data is consistent with the statutory purpose of the APCD, contributes to efforts to improve health care for Colorado residents and complies with the requirements of HIPAA.

What kind of organizations can get information from the APCD?

Both public and private entities may receive APCD reports or data subject to approval of the written request by the DRRC. Organizations that have requested information from the APCD so far include university researchers, divisions of Colorado state government and private firms developing new pricing models for health care services.

What can APCD data be used for? Are there any restrictions on the purposes for which it may be used?

APCD data may only be used to inform projects or support programs that support achievement of one or more goals of the Triple Aim for Colorado: better health, better quality and lower cost. Data cannot be used for the market gain of an individual or an organization. Personal health information can never be shared publicly as a result of a research project or program.

Can an organization charge others for information it gets from the APCD?

Under an approved request, use of the released data is limited to the specific purpose as described in the original application. Further use of the data for a purpose not reflected in the original application would require a new request that fully complies with the privacy and security requirements of HIPAA.

Is there any circumstance in which a private company or individual could get personal, identifiable health information out of the APCD?

HIPAA allows the release of certain, limited data fields for very narrow purposes: public health activity, health care operations, and research activity. Under the terms of the Data Use Agreement all applicants must provide written assurances that no attempt will be made to use any data supplied to ascertain the identity of specific insured individuals or patients, or to report data at a level of detail that could permit a reader to ascertain the identity of specific insured individuals or patients. The DRRC will review every request for APCD data to ensure that no information is released in a way that violates HIPAA privacy and security requirements, and the Administrator will deny any request for data that would violate HIPAA or APCD state statute and rule.

Could a company get a report from the APCD identifying all the people in a given zip code who have a certain diagnosis or have been prescribed a certain drug?

There is no circumstance we can envision in which a company could obtain this data without first directly obtaining individual patient authorization to do so. The company would then have to meet all other data release requirements including showing how this information would improve health, health care quality or lower costs. Similar to HIPAA laws that govern providers or payers, release of specific names of patients can only occur in the most unusual public health circumstances or under research protocols that under HIPAA laws require patient authorization or Institutional Review Board approval.

What happens if an entity misuses APCD data or uses it for a purpose other than that for which the entity applied?

An approved applicant must sign and enter into a Data Use Agreement or contract with the APCD Administrator and agree to the following:

- Restrictions on data disclosure and prohibitions on re-release of the data.
- Prior approval from the APCD Administrator subject to DRRC guidelines is required to publicly release any reports based on the data. The APCD Administrator will carefully review all

materials intended for publication or dissemination to determine whether the privacy rights of any individual would be violated by the release of the information.

- Violation of the terms of the Data Use Agreement constitutes a breach of contract and may:
 - a. Require the immediate surrender and return of all APCD data.
 - b. Result in denial of future access to APCD data.
 - c. Lead to civil action by the Administrator for breach of contract.
 - d. Result in a complaint filed with the U. S. Department of Health & Human Services, Office for Civil Rights, as well as potential civil and criminal action and penalties.
 - e. State Attorneys General are also empowered to take civil action against Applicants who violate the terms of the Data Use Agreement.

How is the APCD Administrator held accountable for the use of APCD data?

The APCD Administrator is required to provide HCPF with an annual report on or before April 1 of each year that includes:

1. Any APCD policies established or revised pursuant to state and federal medical privacy laws, including HIPAA.
2. The number of requests for data and reports from the APCD, whether the request was by a state agency or private entity, the purpose of the project, a list of the requests for which the DRRC advised the Administrator that the release was consistent with APCD rule and HIPAA, and a list of the requests not approved.
3. For each request approved, the Administrator must provide the HIPAA regulation pursuant to which the use or disclosure was approved, and whether a general data use agreement or limited data set data use agreement was executed for the use or disclosure.
4. A description of any data breaches, actions taken to provide notifications, if applicable, and actions taken to prevent a recurrence.

How do you protect the information in the APCD?

The safety and privacy of personal information is a foundational principle of how the Colorado APCD is designed and operated. Not only is data always encrypted and protected but personal information will never appear in any public APCD data output or report.

Data Security: When carriers submit files to the APCD, the datasets are always encrypted and sent over secure connections to Treo Solutions, the APCD Data Manager. Each connection is limited to a pre-determined list of users and IP addresses (internet connections) and reserved for a carrier submitting their data. The servers holding APCD data are "hardened" so that it is impossible to download data to a laptop, USB drive, disc or other device. It is not possible to get remote access to the APCD (e.g., from a Treo employee's home computer). Further, Treo Solutions conducts quarterly "penetration" (hacker) testing of the APCD to identify potential areas of vulnerability.

Elimination of personal identifiers: As data are loaded into the APCD, all personal information is removed and replaced with a separate, unique identification number that does not incorporate any of the personal information. In addition, all APCD data is maintained in an encrypted state both while in transit and while stored. The following illustrates the results of an encryption process:

Un-encrypted Data

Name: Jane Doe
DOB: 1/1/1980
Gender: F
Admit Date: 2/1/2010

Encrypted Data

3INDzLjr2SnG8ma4wvLoXw==z
9D4QK0mn5hE1/2F5+
9D4QK0mn5hE1/2F5
bF6R7dA9rdz3k2de

Controls on how the database is used for analysis and research: Simply stated: personal information will never appear in any public APCD data output or report. All requests for APCD data must detail the purpose of the project, the methodology, the qualifications of the research entity and, by executing a data use agreement, comply with the privacy and security requirements of HIPAA. The DRRC reviews the request and advises the APCD Administrator whether release of the data is consistent with the statutory purpose of the APCD, contributes to efforts to improve health care for Colorado residents and complies with the requirements of HIPAA.

What would a hacker see if he got into the database?

Encrypted information as illustrated above. All APCD data and information is encrypted both during transmission from the health plans and while it is "at rest" or stored in the database.

Could an employer or a law enforcement agency requisition information about an individual from the APCD?

Based on the APCD statute and HCPF rules, the APCD must adhere to federal privacy laws, specifically HIPAA, regarding data disclosures, just as your insurance company must do with respect to claims information. The APCD statute and rules provide no special protection from law enforcement, and there are HIPAA exceptions that, under some circumstances, allow for data disclosures (e.g., certain law enforcement purposes, certain judicial proceedings, etc.). Any data that was released under such circumstances would, however, require that HIPAA's privacy standards be met.



Collecting Health Data: All-Payer Claims Databases

Cost Containment Strategy and Logic

In recent years, several states have established databases that collect health insurance claims information from all health care payers into a statewide information repository. Known as "all-payer claims databases" or "all-payer, all-claims databases," they are designed to inform cost containment and quality improvement efforts. Payers include private health insurers, Medicaid, children's health insurance and state employee health benefit programs, prescription drug plans, dental insurers, self-insured employer plans and

Medicare (where it is available to a state). The databases contain eligibility and claims data (medical, pharmacy and dental) and are used to report cost, use and quality information. The data consist of "service-level" information based on valid claims processed by health payers. Service-level information includes charges and payments, the provider(s) receiving payment, clinical diagnosis and procedure codes, and patient demographics. To mask the identity of patients and ensure privacy, states usually encrypt, aggregate and suppress patient identifiers.

Some states are using all-payer claims databases to identify potential areas for cost savings. It is still too early, however, to determine how effective databases are in helping states shape successful cost containment efforts.

Table 1. Benefits of All-Payer, All-Claims Data Collection Programs

Businesses

- Helps businesses know where they stand with respect to their coverage's costs and included services.
- Provides access to information that gives businesses a better negotiating position.
- Allows businesses to choose insurance products for employees based on price and quality.

Consumers

- Provides consumers with access to information to help them make informed decisions with their health care providers so they can determine which providers and treatments are most effective and efficient.

Providers

- Supports provider efforts to design targeted quality improvement initiatives.
- Enables providers to compare their performance with that of their peers.

Policymakers

- Enables [the state] to identify communities that provide cost-effective care and learn from their successes.
- Allows targeted population health initiatives.
- Allows reform efforts to be evaluated so successful initiatives can be identified and replicated.
- Allows identification of opportunities for further reform.

Source: Oregon Health Fund Board, "Aim High: Building a Healthy Oregon—Final Report," November 2008, http://www.oregon.gov/OHPPR/HFB/docs/Final_Report_12_2008.pdf.

All-payer claims databases alone are not a means of controlling costs. Rather, they provide detailed information to help design and assess various cost containment and quality improvement efforts. By collecting all claims into one data system, states gain a complete picture of what care costs, how much providers receive from different payers for the same or similar services, the resources used to treat patients, and variations across the state and among providers in the total cost to treat an illness or medical event (e.g., a heart attack or knee surgery). In turn, businesses, consumers, providers and policymakers can use the information to make better-informed decisions about cost-effective care (Table 1). All-payer claims databases also are an important source of information for designing and implementing payment and delivery system reforms, such as pay-for-performance, episode-of-care payments, global payments, medical homes and accountable care organizations (all of which are discussed in other briefs in this series).

Target of Cost Containment

Studies confirm the United States spends significantly more on health care than other countries but, on the whole, does not produce better results for patients; it does not receive equivalent value for each health care dollar. Researchers estimate that up to 30 percent of spending on health care is wasted.¹

Without comprehensive data on costs, components, results and demographics of care, it is difficult to identify and eliminate waste. Without reliable information about how and where health care dollars are spent and how patients move through the system, states cannot design effective programs to address both unnecessary and inadequate care to realize health care



system savings. In some cases, all-payer claims databases can be used to identify the most cost-effective providers and methods of care. They also can provide valuable information to assess the relationship between total care costs, prices, use and service intensity, on the one hand, and quality and results of care for different providers, treatments and populations, on the other. Due to data limitations, not all these applications may be possible.

State Examples

■ As of December 2009, all-payer claims databases were operating or under development in Kansas, Maine, Maryland, Massachusetts, Minnesota, New Hampshire, Oregon, Tennessee, Utah and Vermont. The all-payer claims databases in Maine, Maryland and New Hampshire were established partially in response to escalating health care costs and premiums.

■ Most state all-payer claims databases have a governing board or advisory committee that administers or provides recommendations on the operation of, and reports to be generated from, the databases. The committees usually include directors of state health agencies and representatives of key stakeholder groups, such as health insurers, hospitals, physicians, employers and consumers. Some states out-source data management and analytics. Others conduct all or some of the activities in-house. Efforts are under way to standardize data collection processes to make it easier for insurers that operate in more than one state to participate and allow for cross-state data applications and analyses.

■ States that require payers to submit claims data often have statutory penalties for failure to do so in a timely manner (e.g., \$1,000 for each week of delay in Massachusetts, \$500 per day in Oregon and \$100 per day in Tennessee).

■ Legislation enacted in 1995 established the Maine Health Data Organization (MHDO).² Maine is one of 30 states where health data organizations collect and disseminate health care data for policy and market uses. As with other state data organizations, Maine's reporting systems consist of hospital financial and organizational data (including inpatient, outpatient and emergency department data); non-hospital ambulatory service data; and quality data. In 2003, Maine became the first state to require all payers to report claims data.³

Today, MHDO has nine full-time-equivalent employees and an annual budget of about \$1.8 million. Several studies have used MHDO data to identify areas of the health care system that could benefit from specific cost containment efforts. One study, for example, used MHDO data to identify significant unwarranted variation in use and costs of care across the state.⁴ It concluded that, if potentially avoidable inpatient use and high-cost, high-variation outpatient use were reduced by 50 percent, medical spending by commercial health payers could

be reduced by 11.5 percent, and Medicaid spending could be reduced by 5.7 percent. A second study showed Maine uses 30 percent more emergency services than the national average.⁵ Researchers estimated health care payers in Maine could save \$115 million annually by reducing avoidable emergency department use. Maine plans to use its claims database "to identify specific inefficiencies to start working with stakeholders on levers to reduce waste."⁶

■ A 2003 New Hampshire law created the New Hampshire Comprehensive Health Information System (CHIS),⁷ which consists of claims and eligibility data from Medicaid and commercial payers. A website, New Hampshire HealthCost, uses CHIS data to provide comparative information to consumers and employers about the estimated amount a hospital, surgery center, physician or other health care professional receives for its services. HealthCost provides information specific to an insured person's health benefits coverage and also shows health costs for uninsured patients. Employers can use the website's

Benefit Index Tool to compare carriers' health plan premiums and benefits. CHIS data are used to produce health care cost, quality and use reports. One report, for example, found that Medicaid members who received primary care in 2006 incurred \$4.1 million for outpatient emergency department visits for conditions more appropriately treated in a primary care setting.⁸ A second, related report found that Medicaid patients who were frequently treated

in the emergency department often were seen for conditions that probably could have been treated in a primary care office or clinic.⁹ An estimated \$2.1 million could have been saved if each frequent emergency department user had made just one less outpatient emergency room visit during 2006.

■ A 1993 Maryland law created the Maryland Medical Care Data Base,¹⁰ which includes health care practitioner claims (e.g., physician, podiatrist, nurse practitioner) and pharmacy services. Payers that collect more than \$1 million in health insurance premiums annually must submit claims data. Medicare claims also are part of the database. Although the program has access to Medicaid claims, they are not part of the database. The Maryland Health Care Commission uses claims data to report costs and use of professional health services, including variations in charges. A November 2009 report, for example, analyzed expenditures for professional services by privately insured patients between 2006 and 2007.¹¹ The report found average professional services expenditures grew 3 percent in 2007, mainly as a result of increases in the number of services per user as opposed to increases in health care prices.

■ Several states are using their all-payer claims databases for specific cost containment-related initiatives. Utah plans to use claims data to compare the cost of caring for newborns whose mothers had limited or no prenatal care to mothers who had the recommended number of prenatal visits. Kansas intends

As of December 2009, all-payer claims databases were operating or under development in Kansas, Maine, Maryland, Massachusetts, Minnesota, New Hampshire, Oregon, Tennessee, Utah and Vermont.

to use data from its all-payer claims system to develop cost-saving initiatives in its Medicaid or state employee health plan by the summer of 2011.

Non-State Examples

■ The Wisconsin Health Information Organization (WHIO), a private nonprofit organization, is comprised of multiple payers that voluntarily submit claims data to the WHIO Health Analytics Exchange. The organization was incorporated in late 2006 by insurers, employers and providers (e.g., Anthem Blue Cross Blue Shield of Wisconsin, Humana, Greater Milwaukee Business Foundation on Health, Wisconsin Medical Society and Wisconsin Hospital Association). In 2007, the Wisconsin Department of Health and Family Services and Wisconsin Department of Employee Trust Funds became members. Currently, WHIO receives data from 29 percent of health care claims in the state and has commitments from Medicaid and other health plans for submission of claims data that will bring the total to more than 50 percent of the population in 2010. WHIO's goal is to use data to improve the quality, affordability, safety and efficiency of health care delivered to patients in Wisconsin.

■ The U.S. Department of Health and Human Services plans to build a nationwide all-payer claims database consisting of a representative sample of the population. The data will be used to analyze and compare the effectiveness of medical treatments for various conditions. The department posted a pre-solicitation in December 2009 for "a targeted design study to inform the creation of such a database and supporting services, methods, and skills."¹²

Effectiveness of Cost Containment Approach

It is still too early to assess how effectively state all-payer claims databases can help states control costs. Most programs have not been in use long enough to determine their effectiveness in shaping successful cost containment efforts. To date, all-payer claims database programs have not focused on cost containment per se. Rather, the focal point has been using claims information to investigate statewide variations in costs and health care use and publishing data that allow the public to compare health care prices and quality. Some states (e.g., Massachusetts and New Hampshire) have used claims data to identify potential areas for cost savings.

■ At least one state—New Hampshire—has used its all-payer claims database to assess the effect on prices over time of publishing comparative health service prices. The analysis was intended to determine the effect of the state's HealthCost website on prices for health care procedures shown on the website. Before HealthCost was launched, some suggested it could encourage price competition and help slow price increases for procedures listed on the website. Others said higher prices could result due to provider access to their competitors' rates. Still others said prices could become more consistent as providers with high rates lowered them and providers with low rates moved to the mean. In fact, the analysis found no demonstrable effect on providers' prices over time.¹³

■ Evidence exists that analyses of claims data can help evaluate programs that are designed to control costs. A private sector study published in 1989 used claims data to assess the effect on costs of using primary care physicians as gatekeepers in managed care programs.¹⁴ Although researchers did not have access to an all-payer claims database, they used four years of claims data from a large insurer to conduct their study. They found gatekeeping resulted in lower costs during the first year, primarily due to reduced use of specialists, but costs rose during the second year to just below indemnity (i.e., fee-for-service) plan levels.

Challenges

Several challenges exist to setting up all-payer claims databases.

■ Providers may object to payers reporting data about their practices. They may be concerned about how the data will be used, whether it will accurately reflect prices and quality, and if it will account for variations in the complexity of their cases.

■ Consumers may be concerned about the privacy and security of their information, although this often is explicitly addressed in state authorizing legislation and regulations.

■ Large, multi-state insurers, concerned about administrative costs of complying with various state database requirements, may lobby for states to harmonize rules and procedures.

■ A state may not be able to obtain data from employers that have self-insured health plans unless the information is available from the third-party administrators of such plans. Some employers, however, may voluntarily submit claims data, since it is in their interest to compare the prices they pay with what others pay. Information about all users of the health system should be—but often is not—in the database to provide a complete picture of health care use and cost. For the most part, states do not have access to claims data for Medicare patients and have either no or limited data about uninsured patients.

■ The cost of establishing and maintaining an all-payer claims database and publishing and analyzing database information can be significant. Vermont estimated start-up costs for its database would be approximately \$500,000 for FY 2009. The Utah Legislature appropriated \$625,000 in 2008 to launch its all-payer claims database; annual costs are projected to be \$1 million, paid for primarily with state and Medicaid matching funds. In 2008, the Oregon Health Fund Board suggested investing \$400,000 in state funds and \$300,000 in federal funds to establish a database.

Complementary Strategies

All-payer claims databases provide valuable information for structuring and evaluating a number of cost containment strategies. Strategies include payment reforms, such as episode-of-care and global payments; and delivery system reforms, such as medical homes, care coordination, chronic disease management and broad-scale health information technology projects (which are the subject of other briefs in this series).

For More Information

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NCSL has posted supplemental materials and 2010 updates on this topic online at <http://www.ncsl.org/?tabid=19929>.

Acknowledgment

Thanks go to Josephine Porter, co-chair, Regional All-Payer Healthcare Information Council and deputy director, New Hampshire Institute for Health Policy and Practice, and Denise Love, executive director, National Association of Health Data Organizations, who reviewed an early draft of this brief.

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About this Project

NCSL's Health Cost Containment and Efficiency Series describes multiple alternative state policy approaches, with an emphasis on documented and fiscally calculated results. The project is housed at the NCSL Health Program in Denver, Colorado. It is led by Richard Cauchi, program director, and Martha King, group director, with Barbara Yondorf as lead researcher.

NCSL gratefully acknowledges the financial support for this publication series from The Colorado Health Foundation and Rose Community Foundation of Denver, Colorado.



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